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Collection and Determinants of Patient Reported Outcome Measures in Haemodialysis Patients in Scotland

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Abstract

Background: Patient reported outcome measures (PROMs) can evaluate the quality of health in patients with established renal failure. There is limited experience of their use within national renal registries.

Aim: To describe the Scottish Renal Registry's (SRR) experience of collecting PROMS in the haemodialysis population and correlate PROMS to demographic and clinical parameters.

Design: Retrospective observational cross-sectional study.

Methods: Haemodialysis patients in Scotland were invited to complete the KDQOL™-36 questionnaire on the day of the annual SRR census in 2015 and 2016. Questionnaires were linked to census demographic and clinical variables.

Results: In 2016 738 questionnaires were linked to census data (39% of prevalent haemodialysis population). Response rates differed with age (≥ 65 years 42%, < 65 years 36%) [$\chi 2$ p=0.006]; duration of renal replacement therapy (<1 year 46%, ≥1 < 5 years 38%, ≥ 5 years 33%) [$\chi 2$ p=0.002] and social class (Scottish Index of Multiple Deprivation (SIMD) Class 1 32%, Class 2 41%, Class 3 40%, Class 4 48%, Class 5 40%) [$\chi 2$ p<0.001]. There were significant differences in PROMs with age, SIMD quintile and primary renal diagnosis. Achieving a urea reduction ratio of >65% and dialysing through arteriovenous access were associated with significantly higher PROMs. PROMs were not affected by haemoglobin or phosphate concentration.

Conclusions: Routine collection of PROMs is feasible and can identify potentially under-recognised and treatable determinants to quality of life. The association between attaining recommended standards of care and improved PROMs is striking. Individual and population-wide strategies are required to improve PROMs.

Introduction

Established Renal Failure (ERF) is the final stage in the progression of chronic kidney disease (CKD). The prevalence of ERF treated with renal replacement therapy (RRT) is low (0.1% of the Scottish population in 2015).[1] However ERF confers excess morbidity and mortality compared with the general population, making it an important condition for patients and the healthcare service. Both CKD and the treatments given for it can impact upon patients' health-related quality of life (HRQOL).[2] HRQOL deteriorates with progression of CKD, and is substantially reduced by the time patients reach ERF.[3]

Clinicians have traditionally focussed on laboratory metrics to assess the success of treatment of ERF. This can however lead to important problems going unrecognised, such as pain and fatigue, which have a major impact on HRQOL.[4] Patient self-assessments should be included with laboratory metrics when assessing treatment outcomes.

HRQOL can be assessed through self-completed Patient Reported Outcome Measure (PROM) questionnaires.[5] The routine collection of PROMs in ERF is uncommon: in 2014 2 out of 23 European renal registries had experience in collecting them, and there was no consensus on the optimal tool for doing so. Guidance on setting up and maintaining a PROMs programme was subsequently published, recommending the KDQOL™-36 questionnaire for data collection.[6] The use of PROMs to increase CKD patient participation has also been highlighted in the UK Renal Registry 2017-2019 strategy.[7]

We describe the Scottish Renal Registry's (SRR) experience of routinely collecting PROMs in haemodialysis patients over 2 consecutive years. Our aims were to evaluate the practicality of a national renal registry collecting PROMs and assess whether there was correlation between results and routinely collected demographic and clinical parameters. By doing so we hope to gain a greater understanding of our patients concerns, and improve the quality of care provided.

Methods

Patients and Methods

This is a retrospective cross-sectional observational study performed by the SRR. The SRR is registered with the information commissioner under the terms of the data protection act via National Service Scotland (registration number Z5801192). An initial pilot study was performed in May 2015, and a full survey in May 2016.

Within Scotland there are 9 'parent' renal units and 25 'satellite' haemodialysis units. In May 2016 1878 patients were receiving hospital haemodialysis.

Dialysis units invited their haemodialysis patients to complete the KDQOL™-36 questionnaire in the same week as collection of SRR annual census data. Awareness of the process was raised via the SRR steering group member (a consultant nephrologist) from each renal unit.

Questionnaires were distributed by local dialysis nurses. Patients were asked to complete the questionnaire at home to minimise potential bias from completion whilst on dialysis or with dialysis staff present. If patients required assistance or translation they were encouraged to ask a friend or relative to help. With verbal consent, questionnaires were marked with their community health index (CHI) number to allow linkage with census data collected the same week.

KDQOL™-36

The KDQOL™-36 is a validated self-administered questionnaire. It contains 36 questions separated into 5 components: 2 generic (physical functioning and mental functioning) and 3 disease-specific (symptoms/problems, effects of kidney disease on daily life, burden of kidney disease) which cover the different dimensions of HRQOL.[8]

The generic components are contained in the Short Form which has 12 questions (SF-12) that cover physical and mental functioning. The disease-specific component is derived from the KDQOL-SF™v1.3, and contains 24 questions. Disease-specific component scores range from 0 (lowest health rating) to 100 (highest health rating). Clinically significant differences within these composite scores are in the region of 3-5 points.[9]

Statistical Analysis

Patient identifiable responses from the 2016 survey had their data linked to core SRR data and census derived variables. Our analyst is trained in Information Governance and Security. Data was analysed within the SRR therefore clinicians were not able to identify individual responses, maintaining confidentiality.

Demographic variables comprised age, gender, time on renal replacement therapy (RRT), Scottish Index of Multiple deprivation (SIMD) quintile, primary renal diagnosis group (PRD) (glomerulonephritis, interstitial, multisystem, diabetes, unknown/missing) and whether dialysis was in a parent or satellite unit. Clinical variables comprised haemoglobin concentration, urea reduction ratio (URR), adjusted calcium, phosphate, vascular access type, use of the buttonhole technique (whereby blunt needles are inserted via a tunnelled tract) and whether haemodialysis (HD) or

haemodiafiltration (HDF; combining convective and diffusive clearance) was used. Response rate and scores from each of the 5 components of the KDQOL™-36 were compared with each of the above variables using chi-square analysis of contingency tables of the underlying frequencies and one-way ANOVA respectively. Interactive and additive general linear models were performed to identify associations between the variables. Correction for multiple comparisons was not applied partly due to the response rate; we have employed a p value of <0.05. This should be borne in mind when interpreting results.[10]

Pilot Study Survey

A survey was sent to dialysis unit charge nurses following the 2015 pilot. Questions were:

1. Were you aware of our attempt to collect PROMs?
2. If you were aware did your unit participate?
   a) If yes – what barriers did you encounter? Do you have suggestions to improve recruitment?
   b) If no - why not?
3. If your unit participated - would you be willing to again?

Active on Transplant List

SRR data regarding activation on the national kidney transplant waiting list on 31st December 2015 were retrieved for patients starting RRT between 1st January 2010 and 31st December 2014 who had participated in PROMs and were identifiable.

Results

Pilot Study 2015

555 questionnaires were returned from 20 out of 35 dialysis units, comprising 29% of the hospital haemodialysis population. 270 responses had a CHI number (15% prevalent haemodialysis population).

Dialysis Unit Survey

Survey responses were obtained from 26 of the 35 units (74%). Of those who replied, 18 (69%) were aware of the plan to survey PROMs and 15 of these participated (83%). Units who were aware but did not participate indicated that short notice prevented their involvement. Other barriers included patients preferring not to be identified and time pressures. Some staff felt patients may be less honest if they thought their response would be read by people who knew them. Suggested solutions were a post box for questionnaire return and an independent person to assist with administration. All units were willing to participate again.

Following feedback, efforts to raise awareness of PROMs were made through the SRR steering group and dialysis charge nurses. The questionnaire was adjusted to give a clear place to record CHI number and the covering instruction letter was updated.

2016 Study: Response Rate

896 questionnaires were returned (48% prevalent hospital haemodialysis population). 738 questionnaires had an identifiable CHI number and were linked to census data (39% of prevalent population). The median age of respondents was 66 years (IQR 56,74 years) and median time on RRT was 2 years (IQR <1,3 years).

Table 1 shows response rate with demographic metrics. There were significant differences with age (youngest patients having the lowest rate), time on RRT (rate declining as time increased) and SIMD quintile (most deprived responding the least). Response rate was independent of gender, PRD group and dialysis location.

Table 2 shows response rate with census variable. Response rates were higher from patients with a URR over 65%, arteriovenous (AV) access, using the buttonhole technique and those on HDF. It was independent of haemoglobin concentration.

Linkage with Demographic Data

PROMs scores were linked with patient demographic data (Table 3). One-way ANOVAs were performed between each variable and the 5 individual components of the KDQOL™-36. (While statistical significance and clinical relevance are not synonymous, all our statistically significant results had a mean score difference of at least the 5 points thought to be clinically relevant.)

There was a significant difference across all five components of the KDQOL™-36 with age. The younger age groups had lower scores across the kidney disease specific components. Physical and mental composite scores were less separated with age.

There was also a significant difference with SIMD quintile in the categories symptom/problems of kidney disease, burden of kidney disease and physical and mental composite scores (one way ANOVA, $p<0.05$). Those from SIMD quintiles 1 and 2 (most deprived) generally scored lower than those from quintiles 3-5.

In relation to PRD, a significant difference was demonstrated across the 3 kidney disease specific components of the questionnaire and physical composite score. Patients with diabetic nephropathy scored the lowest.

There was no significant difference between PROMs scores with gender, time spent on RRT, nor dialysis provision (main versus satellite unit).

Ethnicity is poorly recorded on the SRR and was not examined. The 2011 census reports 96% of the Scottish population as Caucasian.[11]

Linkage with Clinical Variables

PROMs scores were linked with census clinical variables (Table 4). Patients with a URR over 65% had higher scores in relation to symptoms of kidney disease, effects of kidney disease, physical and mental composites (one way-ANOVA, $p<0.05$).

Significant differences were seen in the symptoms/problem list and effects of kidney disease with calcium level. Patients with hypercalcaemia scored lower. There were no significant differences with haemoglobin or phosphate concentrations.

Patients who used arteriovenous access as opposed to a central venous catheter (CVC) had significantly higher scores in the burden of kidney disease (one way-ANOVA, $p<0.05$), physical and mental composite scores (one way-ANOVA, $p<0.01$). Those who used the buttonhole technique had significantly higher scores across all domains. There were no differences with HD versus HDF.

The use of the buttonhole technique was put through interactive and additive general linear models alongside age, PRD and SIMD quintile. There were no significant interactions for either model indicating the buttonhole technique is associated with improved PROMs independent of these additional variables.

Transplant Data

The percentage of patients who submitted PROMs and were listed for transplant are shown in Table 5. Respondents under 65 years were less likely to be transplant listed than the national average. Respondents 65 years or older were as or more likely to be transplant listed than the national average.

Discussion

There is a recognised need for registries to extend their data collection to include patient-reported data of experience and outcomes; however this is currently not widely done. To the best of our knowledge, this is the first description of routine collection of PROMs across a national renal registry's haemodialysis population.

Nationwide collection of PROMs requires organisation and commitment from all units. Our response rate increased from 31% to 48% following interventions to increase staff awareness and improve patient information letters. We anticipate that institution of PROMs into annual census data collection would increase this response rate further, however patients' ability and/or inclination to participate will always impact on this. When questionnaires were completed, generally all questions were answered. The exception was the question regarding the effect of kidney disease on sex life (incomplete in 13%).

In current clinical practice, PROMs have been used for monitoring patients' progress and in shaping local policy and practice.[5,12-13] Their use has been associated with lower emergency department attendance and increased survival.[14] In the renal population most studies have been observational. Few have addressed causal relationships and whether targeted interventions can improve PROMs. We hope that routine longitudinal collection of PROMs will identify the problems that are important to our patients, and ways to improve these.

Whilst we cannot prove causal relationships between measured parameters and PROMs, we have demonstrated associations. We saw higher PROMs in our more elderly patients ($\geq$65 years), as previously reported.[15] Younger patients on haemodialysis may perceive their illness as more of a 'challenge' or 'threat', potentially as the significant lifestyle changes that occur with ERF impact more heavily upon their multifarious responsibilities.[16] As more young patients will be transplanted than their older counterparts, it is worth bearing in mind that those on haemodialysis may not be representative of their age group as a whole. In addition, our respondents under 65 were less likely to be on the transplant list than the national average which may accentuate this effect.

We also demonstrated a significant effect of socioeconomic background on PROMs, with the most deprived scoring the lowest. This is a concern: these patients already have reduced access to transplantation and have a higher mortality on the transplant waiting list.[17] Those from higher socioeconomic classes with transplants also have better graft and patient survival.[18] As patients with renal transplants experience better HRQOL[19,20] and survival[21] than those on dialysis, developing strategies to reduce these class differences is vital.

Patients with diabetic nephropathy scored lower than patients with other renal diagnoses. This could be related to the higher morbidity and mortality that these patients suffer from cardiovascular disease, alongside other problems such as more frequent loss of vascular access.[22] The incidence of patients starting RRT for diabetic nephropathy is rising with a corresponding increase in the challenge to preserve quality of life for these patients.

We found no significant effect of haemoglobin or phosphate concentration on PROMs. Previous studies have suggested maintaining haemoglobin within the normal range is associated with fewer

physical symptoms.[23,24] There is little information on how phosphate control impacts upon PROMs; however phosphate binders do create a substantial pill burden which itself has a negative impact on HRQOL.[25] The patients completing our survey form a predominantly stable cohort with well controlled biochemical parameters which may explain why these variables have not had an impact in our study.

Patients who dialysed through AV access also achieved higher scores than those who dialysed through a CVC. This may relate to lower infection rates and increased long term patency with fistulae.[26,27]

Our study has limitations. Caution must be used in generalising our findings due to a relatively low response rate and over representation from those aged over 65, those more recently started RRT and those resident in less deprived areas. Additionally, we recognise that in some centres dialysis staff assisted patients complete their questionnaire, which may lead to reporting bias. One unit used an independent patient officer to assist with completion.

This is however the first description of routine collection of PROMs in a national haemodialysis cohort. Attaining recommended standards in vascular access and URR is associated with improved PROMs, highlighting the importance of efforts to reach these targets. We were struck by the associations of age and SIMD with PROMs. Government policy is to address health inequalities and renal services must institute measures to achieve those aims.[28] Measures to actively engage with younger and more socio-economically deprived patients to participate in such surveys and to identify interventions to improve PROMs are needed.

Despite the challenges that exist in collecting PROMs, we believe this to be a worthwhile activity. Quality of life is as important as survival to many patients so determining key contributors to it and optimising these is vital. [29] There is also an association between PROMs and mortality in haemodialysis patients, making it a potential prognostic marker.[30]

We hope our experience will stimulate discussion and enthusiasm for other registries to collect similar data, allowing wider comparisons to be drawn and ultimately leading to improvements in care for patients with ERF and other chronic diseases.

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Tables and Figures

Demographic Variable		**Response rate (%) (No. linked forms/total no. on HD)**	**Significance of difference (χ^2 test)***
Age (years)	18-44	26 (54/209)	p=0.01
	45-64	40 (277/699)	
	65-74	45 (228/506)	
	>75	39 (179/458)	
Gender	Male	38 (413/1089)	n.s.
	Female	42 (325/783)	
Time on RRT	≤1 year	46 (233/508)	p=0.002
	≥1 year <5 years	38 (380/988)	
	≥5 years <10 years	33 (100/300)	
	≥10 years	33 (25/76)	
SIMD Quintile	1 (most deprived)	32 (172/531)	p<0.001
	2	41 (174/428)	
	3	40 (144/363)	
	4	48 (161/332)	
	5 (least deprived)	40 (87/218)	
PRD	Glomerulonephritis	36 (113/317)	n.s.
	Interstitial	39 (167/431)	
	Multisystem	44 (175/396)	
	Diabetes	39 (176/450)	
	Unknown/missing	38 (107/278)	
Dialysis Location	Parent Unit	39 (367/944)	n.s.
	Satellite Unit	40 (371/928)	

Table 1. PROMS questionnaire response rate with demographic variable from 2016 SRR census data. n.s., not significant (p>0.05). * Excluding 'not recorded' or 'not known'; n.s., not significant (p>0.05).

Census Variable		**Response rate (%) (No. linked forms/total no. on HD**	**Significance of difference (χ^2 test)***
Haemoglobin (g/L)	Not recorded	23 (19/82)	n.s.
	<100	36 (111/309)	
	100-120	42 (441/1058)	
	>120	39 (167/423)	
Urea reduction ratio	Not recorded	30 (33)	p=0.002
	<65%	31 (72)	
	≥65%	41 (633)	
Access type	Not recorded	14 (10)	p=0.015
	Central venous access	35 (169)	
	AV Access	43 (559)	
Buttonhole technique	Not known	17 (25)	p=0.006
	Yes	46 (250)	
	No	39 (463)	
Haemodiafiltration	Not recorded	36 (162/456)	P<0.001
	Yes	46 (382/828)	
	No	33 (194/588)	

Table 2. PROMs response rate with clinical census variable from 2016 SRR census data. * Excluding 'not recorded' or 'not known'; n.s., not significant (p>0.05).

		Symptom/ Problem List	Effects of Kidney Disease	Burden of Kidney Disease on Daily Life	SF-12 Physical Composite	SF-12 Mental Composite
		Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Age	18-44 (n=54)	61 (21)	49 (24)	27 (24)	31 (10)	41 (12)
	45-64 (n=277)	62 (21)	52 (26)	32 (27)	29 (12)	40 (16)
	65-74 (n=228)	70 (23)	65 (24)	39 (29)	31 (12)	46 (16)
	≥75 (n=179)	69 (19)	66 (22)	40 (28)	26 (14)	39 (21)
	One-way ANOVA	**p=0.001**	**p=0.001**	**p=0.001**	**p=0.001**	**p=0.001**
Gender	F (n=325)	67 (21)	59 (25)	36 (28)	29 (12)	41 (17)
	M (n=413)	66 (22)	60 (25)	36 (28)	29 (13)	42 (17)
	One-way ANOVA	**p=0.472**	**p=0.848**	**p=0.932**	**p=0.528**	**p=0.476**
Time on RRT (years)	<1 (n=233)	67 (19)	58 (24)	34 (25)	29 (13)	41 (17)
	≥1 < 5 (n=380)	65 (23)	58 (26)	35 (29)	30 (13)	42 (17)
	≥ 5 < 10 (n=100)	68 (22)	64 (22)	39 (34)	27 (14)	39 (20)
	≥ 10 (n=25)	66 (24)	66 (26)	44 (34)	32 (9)	49 (15)
	One-way ANOVA	**p=0.466**	**p=0.079**	**p=0.266**	**p=0.094**	**p=0.143**
SIMD (1 most deprived-5 least deprived)	1 (n=172)	60 (24)	55 (26)	30 (27)	28 (12)	38 (17)
	2 (n=174)	65 (20)	57 (24)	34 (27)	30 (13)	41 (17)
	3 (n=144)	67 (23)	60 (24)	38 (29)	29 (13)	42 (18)
	4 (n=161)	70 (20)	63 (27)	42 (29)	32 (13)	44 (16)
	5 (n=87)	71 (18)	66 (23)	33 (34)	27 (13)	41 (19)
	One-way ANOVA	**p<0.001**	**p=0.06**	**p=0.02**	**p=0.018**	**p=0.041**
PRD	GN (n=113)	64 (23)	59 (25)	34 (27)	28 (12)	42 (17)
	Interstitial (n=167)	67 (21)	61 (26)	39 (29)	33 (13)	43 (15)
	Multisystem (n=175)	68 (21)	62 (25)	38 (29)	29 (13)	43 (18)
	Diabetes (n=176)	62 (23)	52 (25)	28 (24)	26 (12)	39 (18)
	Unknown (n=107)	70 (18)	65 (23)	41 (29)	30 (14)	42 (19)
	One-way ANOVA	**p=0.03**	**p<0.001**	**p<0.001**	**p<0.001**	**p=0.152**
Satellite Unit	No (n=367)	67 (22)	60 (26)	36 (29)	30 (13)	42 (17)
	Yes (n=371)	65 (21)	59 (25)	35 (27)	28 (12)	41 (17)
	One-way ANOVA	**p=0.122**	**p=0.357**	**p=0.546**	**p=0.128**	**p=0.228**

Table 3. Mean and standard deviation PROMs scores based on census demographic variables, and one-way ANOVA.

		Symptom/ Problem List	Effects of Kidney Disease	Burden of Kidney Disease on Daily Life	SF-12 Physical Composite	SF-12 Mental Composite
		Mean (SD)	**Mean (SD)**	**Mean (SD)**	**Mean(SD)**	**Mean (SD)**
Hb (g/dL)	Hb<100 (n=111)	66 (22)	60 (25)	33 (26)	27 (14)	39 (18)
	Hb 100-120 (n=441)	67 (21)	61 (25)	37 (28)	30 (12)	42 (17)
	Hb>120 (n=167)	64 (24)	57 (27)	36 (29)	30 (13)	42 (17)
	One-way ANOVA	**P=0.371**	**P=0.289**	**P=0.482**	**P=0.193**	**P=0.146**
URR	<65% (n=72)	61 (22)	53 (25)	28 (28)	26 (12)	36 (17)
	≥65% (n=633)	66 (16)	60 (19)	36 (31)	29 (17)	42 (22)
	One-way ANOVA	**p=0.031**	**p=0.031**	**p=0.22**	**p=0.015**	**p=0.002**
Calcium (mmol/L)	<2.2 (n=119)	65 (22)	58 (25)	32 (28)	28 (13)	40 (17)
	2.2-2.6 (n=561)	67 (21)	61 (26)	37 (28)	29 (13)	42 (17)
	>2.6 (n=48)	59 (19)	50 (26)	30 (25)	29 (16)	40 (19)
	One-way ANOVA	**p=0.048**	**p=0.011**	**p=0.060**	**p=0.554**	**p=0.397**
Phosphate (mmol/L)	<1 (n=54)	64 (22)	64 (26)	24 (28)	26 (13)	34 (18)
	≥1-<2 (n=519)	67 (20)	60 (24)	38 (27)	28 (13)	43 (17)
	≥2 (n=149)	64 (18)	55 (32)	36 (24)	29 (14)	42 (10)
	One-way ANOVA	**p=0.276**	**p=0.053**	**p=0.531**	**p=0.478**	**p=0.312**
Access modality	AV Access (n=559)	67 (22)	60 (25)	35 (29)	30 (12)	40 (16)
	CVC Access (n=169)	64 (21)	57 (24)	29 (25)	24 (13)	32 (19)
	One-way ANOVA	**p=0.157**	**p=0.166**	**p=0.017**	**p<0.001**	**p=0.003**
Buttonhole	No (n=169)	65 (22)	58 (25)	31 (26)	25 (13)	38 (18)
	Yes (n=250)	69 (21)	63 (25)	25 (30)	25 (12)	33 (16)
	One-way ANOVA	**p=0.014**	**p=0.009**	**p<0.001**	**p<0.001**	**p=0.008**
HDF	No (n=194)	63 (22)	57(25)	32 (28)	28(12)	39 (18)
	Yes (n=382)	66 (23)	59(25)	35(28)	29(13)	42 (17)
	One-way ANOVA	**p=0.156**	**p=0.435**	**P=0.177**	**P=0.105**	**P=0.096**

Table 4. Mean and median PROMs scores based on census clinical variables, and one-way ANOVA.

Age (years)	PROMs Responders Transplant Listed (%) (Number of patients)	Scottish Average Transplant Listing (%)
18-44	46% (25)	74%
45-64	25% (69)	50%
65-74	13% (29)	13%
≥75	2% (3)	1%

Table 5. Percentage of PROMs responders that are transplant listed compared to Scottish average.

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